ADVOCATING FOR CHILDREN AND THEIR FAMILIES WITHIN THE SCHOOL SYSTEM:

special education advocate

By Ruth C. Heitin

As I often tell people, my parents, who died in the late 1980s, would not understand what I do for a living. In their day, the idea of questioning the schools in any way was heresy. Educators always knew best, and teachers always had the last say in all matters of education. However, with enactment of a federal special education law in 1975, local schools had to abide by federal laws and regulations in order to guarantee the rights of students with disabilities. Educational decisions for students with special needs became the joint responsibility of parents and school professionals. Parents not only needed to become advocates for their children, but the field of special education advocacy opened to assist parents in doing so.

Early in 1992, I embarked upon my career as a private special education consultant. I do not usually call myself an advocate because, by definition, advocate means to speak or plead the cause of another, and I am always hopeful that the schools, the parents, and I will work in collaboration and all work for the same cause. Still, it may be necessary to specify what a special education advocate does. Advocates can serve as independent specialists, or, like those in the medical profession, offer second opinions on educational issues. Advocates work for parents, either directly or through a nonprofit group, but their real clients are always the children.

In order to support the child, advocates should be able to support parents through every step of the special education process, from initial evaluation through graduation and beyond, from the initial identification of the child to, if necessary, due process. Advocates are not lawyers, nor can they serve in lieu of attorneys. Their role is one of support for parents in understanding and addressing the issues related to their children's educational needs. Advocates go to meetings with parents, assist in writing Individualized Education Programs (IEPs), help parents understand their child's educational records, clarify the child's educational needs, and help identify and locate appropriate educational services and programs.

Photos by John T. Consoli

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Below, I share with you my reflections or "confessions." Some of these I say with pride, while others I admit with due humility.

Confession #1

The school's reception is not always warm. While the result of the advocate's work is that parents feel empowered, unfortunately sometimes school administrators feel inconvenienced at best and, at worst, they may feel the need to "circle their wagons" against the parents' and advocates' attempts to secure appropriate education and accommodations for children with special needs. Remember, parents always have the right to bring anyone to meetings that they feel has some specialized knowledge related to their children's needs.

Confession #2

All advocates are different. Advocates have no licensing board, and there is not yet an independent professional licensing body for advocates. This means that there is no agreed-upon standardized set of skills that would qualify one as an advocate. Advocates can get training and sometimes certificates from professional groups or private professionals. Unfortunately, though, anyone can call him- or herself an

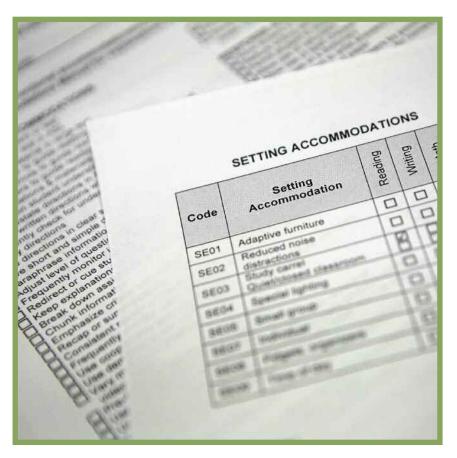
advocate. This means buyer beware.

Generally, there are two types of advocates—those who enter the field following a career in special education, usually as teachers, and those who fall naturally into the role of advocacy after they have secured success for their own children's special needs following a long fight with the schools. I fall into the former category, although it was only a few years into my practice when I found myself advocating for my own son's special needs. Advocates often have different ways of practicing. While there are those who prefer to show up to meetings unannounced, I always call ahead and let an administrator know that I am coming. I also meet and interview the child—after I first read all the background material available about his or her situation. Different advocates have different styles and practices. Parents and school administrators must feel free to ask about an advocate's style, background, and experience.

Confession #3

Not all advocates love to fight. However, no advocate should be afraid to disagree over issues, and it is an advocate's job to be sure that all the tough issues are addressed. Standing up for what we believe in the face of dissension and disagreement is often a necessary part of our job. We have to





keep the child's needs separate from the school's needs as we know they aren't always in sync. Like it or not, we often have to deal with hard issues. Whether or not we "like to fight," often fight is what we have to do.

Confession #4

Advocates nitpick over details because details matter.

Too often, it is the details of the IEP that make a difference. When advocates scour the details, it is for a very good reason. For example, too often schools write accommodations that include the words *if necessary*. Those two words can negate the accommodation by failing to assure that it is offered.

Details can also make a difference in giving parents the information they need to make informed decisions about their children's proposed IEP. For example, recently I had an IEP meeting in which a professional wanted to include several different service models in a single time period. She did this to give herself flexibility: she could observe the child, consult with teachers, or meet directly with the child. The problem with an IEP structured this way is that the parents cannot know the setting or duration of the services offered. Without these details, the parents cannot make an informed decision; they cannot know if their child is getting an appropriate education. After discussion, the individual finally agreed to specify how much time would be spent in each of the services.

Confession #5

Yes, sometimes advocates do know more than school professionals. A good advocate has studied special education law and regulations extensively. School professionals do not always have the luxury to take the time to do this. They rely on school system policies and training to keep them informed about what they need to know. As a result, too often school professionals confuse policy with law. An example of this is that school professionals too often do not address teaching methodology—such as that of a specific reading program—in IEP discussions. However, there is nothing in the law that prevents them from talking about reading methodology and including it in the IEP. A school system's policy or preference should not take precedence over or limit the legal rights granted in special education law and regulations.

Confession #6

Some school professionals find advocates helpful. In helping parents to advocate effectively, I have sometimes had to advise parents to send fewer e-mails or educate them

on what is reasonable and what is not in terms of accommodations. Additionally, an outsider can sometimes make a case for a child more effectively than a school professional, who may hesitate to voice his or her opinion for fear it may be seen as "making waves."

Recently, in writing an IEP for a child with a physical disability, the parents and I gathered information to make a case for more special education help in the general education environment to ensure the child's safety. It was clear to me that the general education teacher welcomed this child in her class, but it was also clear that the general education teacher was relieved both to have additional support for this child and not to have to ask for it. In this case, the parents, school professionals, and advocates all wanted what was appropriate. It is my experience that if school administrators are doing their professional best, they should never be afraid of working with an outside professional.

Confession #7

Advocates are not simply representing parents. I often tell my clients that if they have chosen me to say what they want, they have the wrong person. It is my job to give my best professional opinion based on a great deal of information gathering about what is appropriate for a child—and to do what is best for the child. Of course, the parents and I should



be in agreement over the issues and, before attending any meeting, we work together to reach a mutual understanding and consensus.

I have lost clients over this. Most recently I consulted with the parents of a young girl with autism. My observations and the child's records indicated that this child's behaviors and language skills were so problematic that she needed the support of a small class with very specialized instruction. The parents wanted her to be integrated full time in general education. I could not support their decision. I maintained my professional ethics, and we parted ways.

Confession #8

Parents need the support of advocates now more than ever before. The economic downturn and its resulting tighter budgets and fewer resources in education have increased the natural tension between parents and school professionals. Even though the law mandates that children qualifying for special education receive appropriate services regardless of cost, administrators are always aware of budget constraints and this has naturally shifted their perspective. What was once deemed a necessary service is, in today's economy, sometimes viewed as a luxury that schools feel they cannot afford.

I have seen a tightening of services offered across the board, whether it is in the hours devoted to special education and related services, the provision of technological aids, the support of nursing or paraprofessionals for health and safety issues, or generally the undertaking of any task, such as data gathering, that could consume professional time. Given the school's budget constraints, parents are in the position of having to build clearer and better cases to show what their children need. School officials often believe that parents work from emotion rather than from reason or reality, and the support of an advocate can help ensure that parents' concerns are

appropriately addressed. Further, in this economy, teachers are often reluctant to recommend that a child receive more support, whereas the identification of this need from an advocate can take that pressure off the teachers.

Perhaps my
biggest confession is so important that it does not have a number.

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Here it is: During my practice, I have been able to help parents obtain special education eligibility and services for their children when they could not do so on their own. When parents face a room full of school professionals whose perspectives may differ from theirs, it sometimes helps to have an experienced professional on their side.

Advice for Parents

WITH CONCERNS ABOUT THE EDUCATION OF THEIR DEAF OR HARD OF HEARING CHILD

By Ruth C. Heitin

- Consider an advocate. Advocates may be skilled evaluators of a child's educational program, and they are sometimes more successful in obtaining services than the parent or other educators.
- Don't be upset if the school tries to discourage your decision to have an advocate involved in your child's education. You have the right to seek counsel from whatever expert you choose—and to bring that expert to meetings.
- Select an advocate based on references from an organization or individuals you respect.
 There is no licensing board for advocates.
- Provide the advocate with all the paperwork concerning your child. If the advocate does not ask for this, consider looking for someone else.
- Expect the advocate to show interest in the details of your child's IEP. As the saying goes, the details are where one finds both angel and devil—effective strategies and useless speculations.
- Consider the advocate's opinion. A good advocate will not mimic your point of view or embrace it without thinking about your position. A good advocate will place your child first.

